

Raised Bill Number 5450 – AN ACT CONCERNING THE PALLIATIVE USE OF MARIJUANA

Sean William Hearn's Testimony  
Age 10

My name is Jackie Hanish. My friend, Kim Hearn, is the proud mother of Sean W. Hearn. Sean is a 10 year old boy who has been fighting for his life since he was 5 months old. Sean is living with a very rare and debilitating form of childhood onset epilepsy called Lennox Gastaut Syndrome. Children with Lennox Gastaut Syndrome typically suffer with multi and intractable seizure types. Sean has over 50 seizures a day!

Sean is completely dependent on his parents for all of his care. He is confined to a wheelchair, he is unable to sit without someone holding him or stand without equipment. Sean is unable to speak. Sean is fed via a feeding tube and takes a combination of 5 seizure medications 3 times a day.

Kim, her husband Chris, and Sean's doctors have tried to control Sean's seizures through diet (Ketogenic Diet), medications and alternative therapies. With the onset of puberty rapidly approaching (which typically makes treatment even more difficult), Kim and Chris feel like they have tried all of the current available options and are afraid of what the future holds for their precious son.

With the number of medications Sean's takes daily there are side effects. The most notable are extreme fatigue and loss of personality. With every new med we add they lose more of Sean.

The work that is being done with cannabis oil (**which contains no more than 0.3% THC**) in Colorado and across the country has given families like mine a reason to hope.

Sean's health and well-being is the utmost priority to Kim and her husband Chris. Every decision they make is with Sean's best interest at heart. I beg that you legalize cannabis oil for minors and allow it to be a treatment option in Connecticut so that each family can review this option with their specific medical team and determine if their child could benefit from it. Please give Sean and all of the other children in similar situations, a fighting chance. Please give these parents the right to choose.

I beg you to pass this bill.

With gratitude and hope,

Jackie Hanish  
6 Old Dairy Lane  
Shelton, CT 06484  
203.922.1155

